

Lessons *of the* Spirit



A Christian
Spiritual Companion
for Your Breast Cancer Journey

Rhonda Joy Robinson

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Chapter I

For the Patient – Coping with Diagnosis and Treatment: Faith in Practice

As Jesus walked along, he saw a man blind from birth. His disciples asked him, ‘Rabbi, who sinned, this man or his parents, that he was born blind?’ Jesus answered, ‘Neither this man nor his parents sinned; he was born blind so that God’s works might be revealed in him.’

– John 9:1-3

The moment of diagnosis is not the time to worry about repentance

Why is God doing this to me?

What did I do to bring this on myself?

In my experience as both a patient and a priest, these are the most common questions that we who have been diagnosed with cancer immediately ask ourselves. They are really two parts of the same ancient question: is disease punishment? There are, of course, ways that our behaviors predispose us to illness. Some are obvious (smoking, poor diet, lack of exercise), others less so (food and drink loaded with chemicals, hormones and antibiotics, which these days are hard to avoid even if we are vigilant). There are also factors out of our control known to raise the likelihood of cancer, such as genetic predispositions, or exposure to certain types of radiation or chemicals.

But no matter what the cause, the question of personal guilt is to be avoided at all costs immediately following a cancer diagnosis, as it is deeply counterproductive to healing. *This moment* is not the time for deep soul searching; rather, it is the time to pray for the strength to face the disease and to pull one’s psyche together in order to find the right doctors and treatments. For me, there would be time enough for soul work later on; but in the beginning, I needed to put aside those questions so that my body and soul could be open to healing, not mired in obsession about how I got into the present predicament.

And Moses cried out to the LORD, “O God, please heal her.”

– Numbers 12:13

Who is my doctor? Allowing God to lead you to the right healer

If you have received a cancer diagnosis, a doctor gave it to you, but that does not mean that this is the doctor is the one who should treat you. And because cancer is not a “one size fits all” disease, there is a bewildering array of doctors, philosophies, and treatments out there that can easily overwhelm the average layperson. Despite the potential for confusion, there are strategies to follow in making the most important decision of your journey through cancer: finding the right doctor and medical team. Here is a shorthand guide to the process:

First – Talk to people you know and trust who have been treated for a similar type of cancer about their experience with their doctors and their treatment.

At the outset, your primary care physician or your gynecologist will refer you to a cancer specialist (often a surgeon, possibly an oncologist); start with these references. But finding your primary cancer doctor often goes well beyond this initial referral and opens out into a broader search. Here is where you will want to research other cancer patients’ experiences. This step comes with a caveat: because no two people will ever have the same journey, do not expect anyone else’s story to be entirely congruent with your own. What you are looking for here are not specifics of other patients’ treatments (which may not apply to your situation), but rather the level of confidence and trust the patient has for her doctor³.

Notice that I said “confidence and trust,” NOT general popularity, rank at their hospital (no matter how prominent), or even credentials. It is also not necessarily true that the doctor who has treated multiple people in your neighborhood, workplace, or even members of your own family is the right doctor for you. Of course, you want a well-trained doctor with the appropriate degrees, affiliations, and accreditation who works at a well-respected health care facility. But beyond these basics, you want to hear a patient talk about her doctor with enthusiasm, high esteem, and genuine personal regard. You are searching for a doctor you can have both confidence in and a comfort level with, before entrusting your life to her or him for treatment.

There is good and bad news here: the bad news is that so many people are being treated for cancer these days that chances are there will be many – perhaps too many – personal anecdotes and recommendations to draw from. The good news is that as you sift through these the chances are high that you will find at least one or two good leads to the doctor – and the affiliated team and facility – who will be right for you.

Here’s how I found my breast surgeon. Shortly after my initial diagnosis with a surgeon I didn’t like or trust, I put my name on an email prayer tree associated with the Cathedral Church of St. John the Divine, my first church family. Within minutes, return emails and phone calls began pouring in from people I knew who wanted to offer their prayers or commiserate. Most had cancer stories of their own, but one stood out.

An acquaintance of mine whom I hadn’t spoken with in over ten years phoned, and shocked me by telling me that she had undergone a double mastectomy. She asked me if I

liked my doctor, and when I replied that no, in fact I intensely disliked the doctor who diagnosed me, she started raving – in a good way – about her doctor and the whole breast cancer team; she couldn't say enough good things about them. *That's* what you want to hear. She said her breast surgeon was all the things that the one who diagnosed me was not: a highly skilled and experienced surgeon, but respectful, warm, responsive to questions, very individualized in her approach to treatment, conservative but safe in her approach to surgery, and not arrogant in the least. In addition, she said that the team, consisting of surgeon, oncologist, staff, and technicians, works closely with each other and with you, communicating well, and always respecting and involving the patient.

That sounded good to me for several reasons. First, my friend clearly had a very positive experience during a very trying time, not only with this particular surgeon, but also with the entire staff and hospital. Second, I heard in her voice enthusiasm, esteem, and regard for her surgeon. Third, my family and I had already had an excellent experience at that same cancer center when my stepfather had melanoma surgery by a different doctor two years before. So I made an appointment, and my friend's recommendation of this doctor and hospital were quickly confirmed. What started out officially as a "second opinion" quickly turned into the only opinion that mattered – I had found my surgeon, team, and medical center.

Second – Don't hesitate to get at least two opinions on surgery and/or treatment options.

Second opinions – and sometimes third and fourth ones – should be encouraged by your doctor and taken advantage of by you. Different doctors may have different options for treating the very same cancer, and all options are worth exploring. Sometimes you will hear the same treatment options from multiple doctors; then the task reduces to picking the doctor and hospital for your treatment. The main point is this: if your doctor discourages you from talking to another doctor or appears threatened by your seeking another doctor's opinion, *run*, don't walk, away from that doctor. Remember: your life is at stake here, not the doctor's ego.

Finally – Once you've chosen your doctor, make up your mind to ask whatever questions come to mind, but to ultimately submit to the doctor's treatment plan.

This was my toughest challenge, because like many of us, I have had dreadful experiences with doctors in the past, so I tend to be combative with many of them. But once you've prayed and thought through your choice of doctor to the point of comfort, remember that God has put that person and team into your life to heal you, and that *God will work through the doctors you chose and the treatments they recommend for you*. This is the wrong time to be playing games with your own sense of control; let God deal with letting you know if your treatment is veering off track and something needs to change. If that's the case and your doctor is not responsive, get a different doctor. But don't react with suspicion and resistance out of habit or denial about the position you're in. Of course, doctors in this field have much experience with patient anxiety, resistance, and anger, but they are human, and you want to cultivate a partnership with your doctor based on mutual respect, not reflexive combat.

³ Throughout this book I will use feminine pronouns to refer to the breast cancer patient, although breast cancer can

and does occur in men.

He who dwells in the shelter of the Most High, abides under the shadow of the Almighty. He shall say to the Lord, "You are my refuge and my stronghold, my God in whom I put my trust." He shall deliver you from the snare of the hunter and from the deadly pestilence. He shall cover you with his pinions, and you shall find refuge under his wings; his faithfulness shall be a shield and buckler. You shall not be afraid of any terror by night, nor of the arrow that flies by day; Of the plague that stalks in the darkness, nor of the sickness that lays waste at mid-day.

– Psalm 91:1-6 BCP

Who will take care of me?

Who will take care of you? The short answer is: God.

God will care for you through people in your life – certainly through your medical team and their treatments, perhaps through your loved ones, and possibly through some people you never would have expected. But strap yourself in and get ready to be surprised, because sometimes the angels God sends are those you least expect.

Perhaps you have people in your life with whom you have long-term, very intimate relationships: your spouse, family members, faithful friends; I pray that they will faithfully accompany you on your journey. But perhaps someone you are certain will stick by you will prove unequal to the task, for who-knows-what reason. If a special person falls away, it wouldn't be the first time that a relationship crumbled in the crucible of a serious illness.

But that doesn't mean you will be alone. God is always prepared to provide others who may not be able to fill the entire role that your special person once played in your life, but they will be able to meet your needs, *if* you are open to allowing them to do so. The catch here is that quite often those who are willing to be most helpful to you are the ones you least expect: people you dislike, look down upon, find annoying, or just plain couldn't stand 20 before you were diagnosed. This is not surprising. Cancer challenges you to re-evaluate every area of your life, including your relationships, and you may very well find that people you judged as not worthy of your time or affection will suddenly show themselves to be of greater depth, generosity of spirit, and compassion than the ones you had valued more highly. Accept their help, for both of your sakes – then watch in amazement and see how new relationships take off. The rewards will be greater than you can imagine.

For since death came through a human being, the resurrection of the dead has also come through a human being; for as all die in Adam, so all will be made alive in Christ.

-1 Corinthians 15:21-22

Will I die?

Will you die? Let's be honest. Yes, you will die. All of us will die, someday. But not necessarily of cancer, and probably – none of us can say “certainly” – not today. This means that you are *alive* today, which is no small gift, and one of the most important lessons that cancer can teach us.

Encountering mortality after a cancer diagnosis is often deeply dislocating, but it can teach us more about the reality of the gift and fragility of our physical being than our former lives ever did. The fact is that all of us alive on the earth today are in the same situation whether we are facing a serious health challenge or not: none of us knows how long we are going to live, or in what manner we will die.

All of us know people who have died suddenly and unexpectedly, just as all of us know people who were expected to die but who “pulled through” critical illnesses or injuries. We tend to think of this last group as outliers from the norm, but they are signs of the larger reality that is spoken of repeatedly in the Bible: that none of us is promised another hour of life, none of us knows when our souls will be required of us, and the ultimate decision is God's. A cancer diagnosis drives home that reality.

How we handle that new found reality will affect the quality of our remaining days. Most of us will find it impossible to return to an old pattern of thinking that was based on the groundless assumption that we have plenty of time to waste because our time is limitless. Most of us will begin to value the most important aspects of our lives, like precious relationships and meaningful work. And most of us will be thankful for each day that is given us now that we know that there will be a day when we will certainly move on from this world into the next. These are gifts that a cancer diagnosis can give us, but we have to decide to receive them for them to manifest in our new lives.

Refrain from anger, leave rage alone; do not fret yourself; it leads only to evil.

– Psalm 37:9 BCP

Fear and fury

Extreme fear and furious rage accompany many people through their cancer journeys. Sometimes paralyzing fear grips a patient at the time of diagnosis – I was one of these people – but sometimes as fear releases its grip anger rushes in to fill the void. Some cancer patients are both fearful and angry from the start; still others never experience the paralyzing fear but start out angry and remain so.

Fear and anger are closely related. Both emotions arise from a perceived loss of control over our circumstances – many times we lash out in anger to avoid giving in to, or even compensate for, feelings of deep fear. You're not sane if you don't feel some degree of fear when you are first diagnosed with cancer, along with some sadness, too. But anger is a different story.

I was fortunate – I did not experience anger or fury during my journey. Many people would ask me, “Aren't you angry?” but I never could figure out exactly who or what I should be angry at. At myself for somehow “giving” myself cancer? At the doctors for telling me that I was sick and then giving me therapies that made me feel worse than before I was diagnosed? At the disease for robbing me of my health, what I knew as “my life”? Or at God, for permitting this to happen to me? Those of us familiar with scripture immediately gravitate to the Book of Job during times of suffering. Was I like Job? Like Job, should I be not only bewildered but also angry at my misfortune because I have tried to live a good and faithful life, and therefore think I don't deserve suffering?

None of these options made sense to me. The only productive side I could see to anger – and I think that this is the basis of the fury of many cancer patients – is that it confers a sense of control. Anger is something no one can take from you, unlike your health, even your life. So it is hard, if not impossible, for some people to let go of it, because it feels like a lifeline to existence: *I am angry, therefore I am*. Rage is a statement of presence that forces others to deal with you on your own terms, not those of the disease. But anger does not help healing and cannot draw others who can help you. It can only serve to drive them away.

Like all emotions, anger has a spiritual dimension. If you suffer from extreme anger that you can't seem to shake on your own, pray to God to be released from it, and ask others to pray for you as well. Your anger is not a sin, it is a trial – a trial within the larger trial of cancer. As a priest I've seen incredible healing of the souls in those who are willing to let go of anger during the course of a serious illness. That is one of the most valuable lessons we can allow the Holy Spirit to teach us about healing while we are in treatment.

I appeal to you therefore, brothers and sisters, by the mercies of God, to present your bodies as a living sacrifice, holy and acceptable to God, which is your spiritual worship.

– Romans 12:1

Half of life is just showing up...

I'm not sure who first said, "Half of life is just showing up" (the quote is often attributed to Woody Allen), but whoever came up with those words opened an unwitting window on the psyche of a cancer patient.

Whether we are terrified or furious or both, we don't stand a chance unless we show up for the tests and treatments that make destroying the cancer possible. Nevertheless, I found waking up and getting out of the house and to the hospital on a test or treatment day harder than anything else. Harder because, unlike most days, we know that those days are likely to be life changing, and harder because we don't know whether the treatment or test will result in hopeful or discouraging news. Harder, too, because at the end of the day we know we might feel much worse than when we started off, especially if the day is a "chemo day." And harder because, no matter what else is going on that day in the rest of the world, we will be forced to spend that day confronting a potentially deadly disease, whether we feel up to it or not.

Not wanting to show up for testing or treatment is perfectly normal: no one wants to present herself for something that might lead to suffering without a good dose of trepidation, which for me would start about 48 hours in advance. The best doctors and nurses know this, and take steps to "take the edge off," as well as show respect for the courage it takes to simply show up – my chemo nurse would very humbly thank each of her patients for their bravery as she started each chemo drip.

There were four ways I found that I could gather the strength to cope with testing and treatment days. First, I put the day into perspective by realizing how few days they totaled during the course of my life. In my own life I had eight chemo treatments over sixteen weeks, which adds up to a little over a week of my then five decades of life, which is a vanishingly small amount of time. Second, I notched treatments off in my mind, the way prisoners count the days to their freedom by marking them on their cell walls: the eighteenth radiation treatment meant I was more than halfway through my schedule of thirty-seven as I checked them off a day at a time. Third, I used these especially difficult days as an opportunity to be grateful for the days I *didn't* have a test or a treatment, and so my sense of gratitude for my life took on new grace and power.

Fourth – and most important – I prayed while undergoing the test or treatment. Binding myself to God in prayer was absolutely invaluable, and a true source of strength. I used very short prayers, the shorter the better, so they could be repeated over and over like a mantra. Here are some short but effective prayers:

If God is for me, who can be against me?

I can do all things through Him who lives in me.

Give thanks to the Lord, for He is good, God's mercy endures forever.

Some people recite the Jesus Prayer, the Hail Mary, the Trisagion, or the Lord's Prayer. Singing hymns to yourself can work, too. Prayer in any form can get you through *anything*, even the chemo treatment you desperately don't want to take.

Rhonda Joy Robinson is a breast cancer survivor and an Episcopal priest currently serving as priest-in-charge of the Church of the Intercession in Manhattan. Born of Jewish heritage, she was baptized in 1987 at the Cathedral of St. John the Divine in New York City, where she was one of the founding wardens of the Cathedral's Congregation of Saint Saviour. Since her ordination to the priesthood in the year 2000, Rhonda has served as an assistant priest at the Church of the Heavenly Rest and as priest-in-charge at St. Philip's Episcopal Church in Harlem. A graduate of Barnard College, the Columbia University Graduate School of Arts and Sciences, and Union Theological Seminary, Rhonda enjoyed a long career in dance, music, and theater production prior to her ordination. For 28 years she was on the staff of Barnard College as the Technical Director of first the Theater and then the Dance Department, while simultaneously working as a freelance technical director, lighting designer and production manager in New York City and worldwide.



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